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FULL REPORT

Part 3 - Identifying barriers and facilitating factors to improve the quality of AUD aftercare: a focus group study



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Voorwoord

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Background

Alcohol use is a major cause of morbidity and mortality. According to a recent WHO-report the use of alcohol is a component cause of more than 200 disease and injury conditions in individuals, most notably alcohol dependence, liver cirrhosis, cancers and injuries (1). Mortality attributed to alcohol use is estimated at 1 in 7 deaths for men and 1 in 13 deaths for women (2).

In Belgium according to the Belgian health survey 10% of the Belgian population has an alcohol use disorder (AUD) (based on the CAGE-criteria) and Rehm et al.8 state that 5.4% of Belgian men and 1.9% of Belgian women aged 18–64 were affected with alcohol dependence (3-4).

In addiction medicine there is now a broad support for AUDs to be a chronic health problem, presenting many similarities with other chronic diseases in heritability, course, risk of relapse, and response to treatment (5). Yet, in contrast to other chronic diseases, the condition is extremely undertreated. A European study (including Belgium) found that only 8% of persons with an alcohol problem had consulted some form of professional assistance in the past year (6).

This treatment gap is the result of 2 major processes. First, it has been shown that there is a long delay before individuals with AUD seek help. Multiple barriers at the level of the individuals with an AUD, the health professionals and also the socio-economic context have been identified (7-8).

Second, many individuals entering treatment are discharged or drop out prematurely. The reasons for this are multiple. Current care for patients with AUDs is often inadequate and based upon practices with little or no evidence of effectiveness (5, 9-11). In addition, it relies heavily on an acute treatment model, providing detoxification programs, sometimes followed by specialty treatment rehabilitation programs, but without proactive efforts to ensure continuity of care thereafter (5). Finally, there is no integration of care. Medical treatment, mental health care and substance abuse programs are often provided separately, and different healthcare settings (inpatient, outpatient and partial hospitalization) generally function independently.

In continuing care for patients with AUD, multiple isolated continuing care interventions have been described in a wide variety of formats and modalities (10, 12). Nevertheless, fully integrated care programs (ICP) have never been developed (13).

Objectives

The final aim of the Belgian ICARUS project is to develop an ICP for the continuing care of patients with alcohol dependency. To develop such an ICP, a systematic approach should be applied based on an internationally validated approach (14).

In this project we addressed the following specific objectives

1. to identify interventions for AUD sustaining the principles of integrated care and to evaluate their effectiveness;
2. to systematically develop evidence-based indicators to measure the quality of continuing care for AUD;
3. to assess continuing care for AUD currently provided in Belgium;
4. to identify barriers and facilitators related to current continuing care for AUD.

We defined 'continuing care' as the treatment phase following an alcohol detoxification treatment.

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Identifying barriers and facilitating factors to improve the quality of AUD aftercare: a focus group study.

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Background

The aim of the ICARUS project is to improve continuing care for patients with AD. For this purpose, we intend to develop an integrated care program (ICP) based on our ongoing research. Our hypothesis is that the implementation of an integrated care program (ICP) offered to patients after initial rehabilitation treatment in a specialty care setting, would improve the quality of aftercare and reduce the risk of relapse. Moreover, the developed ICP could serve as a generic model for wider implementation in addiction care.

The first step of the project was the performance of a systematic review. Then quality indicators were developed and current aftercare was inventorised using an online survey.

This report covers the last step, which is a qualitative study about patients' and caregivers' views on barriers and facilitators for good quality aftercare.

Methodology

Focus groups were conducted with psychiatrists, nurses, social workers, psychologists, patients with AUD and their relatives/informal carers. The methodology was guided by a 'grounded theory' approach (Strauss & Corbin, 1997), which means that we did not start from a specific theory. Instead, we examined problems and facilitators in daily aftercare practice and developed a conceptual framework consistent with what we were observing (phenomenological approach).

Participants

Purposive sampling was used to recruit participants that are involved in aftercare for patients who received treatment for alcohol dependence in a specialty treatment centre. In this pool of participants, we aimed for variability in setting (ambulant and hospital care) and region (Dutch and French speaking region). Persons were recruited of whom the project members knew they have ample experience in aftercare. We also enrolled caregivers who had indicated in our previous survey they wanted to collaborate in further research. The participants signed an informed consent and a short questionnaire to collect data on the following demographic variables: profession, number of years' experience, gender and age. For patients we queried the number of detoxifications and the year of the last detoxification.

Focus groups

In total 7 focus groups were held.

Five groups consisted of different mental health care providers with generally over 5 years of experience and from different regions: Antwerp, Hasselt and Sint-Denijs-Westrem (3 Flemish speaking) and Brussels (2 French speaking including caregivers working in Wallonia). Eleven men and twenty female providers participated all in mixed professional groups. The following

professions participated: psychiatrists (n=8), psychologists (n=8), nurses (5), general practitioners (2) and social workers (6), other (drug/justice related care (2). Seven professionals provided ambulant care, 16 intramural clinical care and the remaining 4 provided both. Eighteen health care providers had more than 10 years of experience in the field.

The remaining 2 groups consisted of Dutch speaking patients and ex-patients, sometimes with their partners present in the group. They met in the Pittem centre (Flanders). The groups included homogeneously 17 laypersons to allow free expression of views. Moreover, 5 ex-patients participated (2 women/3 men).

The experience of patients and ex-patients with other care facilities appeared clearly during the focus group discussions; (ex)-patients had followed between 1 and 6 admissions for detoxification (mean 3); many had been or still were involved in a selfhelp-group or different types of aftercare groups.. Three couples (had) received couple aftercare and some ex-patients were maintaining attention to their alcohol dependence due to involvement in voluntary work.

Despite the limited number, the FG of lay people composition was purposefully varied to allow expression of different views about a large variety of settings and informal caregivers. No French-speaking client groups were organized due to practical problems and limited time schedule.

Data collection

The focus groups participants were requested to freely discuss their views on aftercare. Groups were moderated by different members of the project group, who partially oriented discussions towards previously specified relevant domains of aftercare. Two other members took notes of non-verbal behaviour of participants. A consent form was signed by all participants. During each group at least one (TB or DZ or both) of the main researchers was observer. The discussion was video and audio recorded and transcribed verbatim and revised (TB or DZ). Videos enabled identifying fragments from the same speaker. Immediately after each focus group, a summary was created from field notes and recordings.

Guide book

At start, an icebreaker was used (sharing some unknown issue about oneself) and the the care setting they are working in was presented. An overview can be obtained upon request. The moderator was instructed to initiate discussions specifically around following questions:

How can care be improved after detoxification?

1. What is running well?
2. What problems do you see?
3. What could be improved?

Group observations

In general, the caregivers were positive about their colleagues' proposals but also interesting discussions arose from the wide variety of models and institutions. It is apparent that better

communication and collaboration in evaluation of essential elements would be fruitful. Participant professionals clearly demonstrated a positive attitude towards further collaboration in this way.

Specific solutions for continuing care problems were discussed in different groups, relating often to specific opportunities in some centres; e.g. the use of open access mental health (St.- Denijs Westrem) and online support (St;-Denijs Westrem, Hasselt), law enforcement initiated care (Hasselt) and communication with general practitioners (Antwerpen and St Denijs Westrem, each 1 GP participant).

Special functions in the French speaking groups were a representative of a non-specialised psychiatric department in general hospital setting, a therapeutic community and a homeless shelter.

The patient groups generally had positive views on actual care programme with active aftercare groups (predominately organised within the psychiatric hospital where they had received treatment) They attach great importance to discussions about relapse prevention and recognizing and managing the factors that play a role in it. Primary coding

Two researchers from different disciplines separately coded the discussions, at first using a phenomenological approach. Primary coding in Nvivo 10 was performed independently by at least two researchers (LP, TB, DZ, CM, EL). Primary codes were compared and disagreements were resolved by discussion and consensus. For all focus groups, either TB or DZ coded to ensure cohesion in the nomenclature of the codes. We used a constant comparative method (Strauss & Corbin, 1998), a non-binding codebook was made and updated over the course of the coding process.

By application of the constant comparative method, we compared newly gathered texts with previously collected fragments in order to develop coherent categories of responses. This open coding allowed identification of basic concepts.

Axial coding

In a second step, axial coding related codes to secondary categories or subcategories. Two researchers (TB, DZ) related codes to the main categories 'barriers' and 'facilitators' for initiation and/or retention in (after)care for AUD. Similar concepts were combined into a three levelled tree structure (DZ) (selective coding, Strauss & Corbin, 1998).

An additional coding check was also made using Nvivo word counting and text search functions for most widely used words by the participants; relevant nodes (existing or new) were added to the surrounding text fragments e.g. 'drop-out', 'relapse' and 'herval'. Matching French and Flemish terms were grouped to the same nodes to permit joint analysis of French-speaking and Flemish text fragments e.g. 'aftercare', 'cure' and 'postcure'.

Model development

The final step was the construction of a theory, based on relationships between main concepts and refined codes. Using the coding tree, LP first analysed the two patients' focus groups separately from the provider focus groups.

DZ reviewed the codes given to all text passages relating to 'aftercare' or 'cure' and 'postcure' specific of the FG of care givers. Combined with original coding, this yielded a specific analysis of answers to aftercare problems according to providers.

Text fragments of the main concepts in the statements of patients and professionals were further explored and relationships were indicated in Nvivo. Using the graphic Nvivo display module, the resulting models were refined as shown below.

The models used by the two approaches were compared and jointly hypotheses for improvement of aftercare were formulated

Research questions

Following questions are analysed in this report:

1. What are the main barriers and facilitating factors for effective care following intensive alcohol detoxification?
2. How do factors identified for patients and provider groups compare?
3. What is the consequence for quality of aftercare and the retained indicators in the ICARUS study?

Main results

I. Views of lay participants

1. Main concerns

Continuity of care, availability of professional support after detoxification as well as coping with external stressors were the main concerns expressed in the patients' FG.

2a. Barriers according to lay focus groups

1. Attitude
 - Due to inappropriate feeling of safety and returning to regular habits
 - Not taking responsibility due to induced passiveness during hospital period
2. External problems after detoxification period
 - Drop out in aftercare group
 - Due to practical problems
 - Returning to work to quickly
 - Dangers at release
 - Family denies illness

- Hidden drinking (for spouse)
- Work overload when returning home
- Care after detoxification limited to 2 years
- Care peer group too far away
- AA groups
 - Too 'religious' or 'sectarian'
 - Too large groups
 - Too much repeating problems
- Reasons for relapse
 - Drinks offered at work
 - Drinking partners
 - Drinking due to relational problems

Drinking due to comorbidity

2b. Facilitators according to lay focus groups

According to focus groups, including patients and their wives, the continuing care process needs special attention for following points:

- 1) Increase of internal awareness of the definite scope of dependency
- 2) Organization of the aftercare process with available facilities to ensure active support and follow up
- 3) Attention for external factors and coping with triggers for alcohol use

Model 1 summarises the elements that are considered by clients and spouses to be essential in success of aftercare.

1) The internal gradual awareness rising

The trial and error experiences highlighted the need of resilience about (re)use after detoxification among professional caregivers. Change of lay attitude against alcohol use is a lengthy process.

Open discussion of such experiences in the ambulatory peer groups are important to realise personal limits and factors in the home situation that lead to reuse. After detoxification a gradual

increase of insight should be pursued; different modalities should be combined to yield this awareness: tailored professional help as well as aftercare groups; self-help groups received credit but are considered by some participants as less effective than structured discussion in aftercare groups which allow for more balanced attention to group process and personal needs.

2) Organisation of the aftercare process starts with admission

Following needs were expressed:

- a) More continuity of care, also during earlier and subsequent periods
- b) Usefulness of aftercare group and conditions for their good functioning
- c) Additional provision of continued individually tailored care

A. Need of more continuity of care with earlier periods and thereafter

The prevailing ideas expressed by patient groups indicate the need for more continuity of care between pre-detoxification period, admission, intramural and continued care. They indicate actual lack (and hence need) of continuity of care.

- Points for attention upon admission

When external care providers are involved, their availability and involvement in the aftercare period is more readily obtained. The situation at home needs attention shortly after admission.

- During detoxification
 - i. The need for more awareness and careful planning of the transition between intramural and extramural care
 - ii. A particular aspect here is the need to involve informal caregivers such as spouses. Otherwise they stay home with unchanged views on the alcohol use problem
- After the formal ending of aftercare
 - i. the need for a possibility to connect again to after care groups or special individual support remains longer than two years
 - ii. Self-help groups are well appreciated, but existent AA are sometimes considered as to sectarian and religiously inspired, opposed to professionally led aftercare groups,

B. Usefulness of aftercare group and conditions for their good functioning

The aftercare group breaks the feeling of loneliness, allows sharing frustrations and experiences with people considered as peers. Participants also indicate that the moderation by professionals of such groups is important.

C. Additional provision of continued individually tailored care

Participants realise the transition between the institutional environment to the home situation is a big step from the protected environment to the old situation where triggers for reuse are still present. Negative experiences with pressure to drink at work, non-understanding by their partners, who did not get any explanation or emotional support-, or underlying socio-financial or housing issues. Involving the home front in an early stage of care is felt important; attention should also be given to particular supportive strategies. Leaving the institutional setting often stops the individualised psychotherapeutic support due to non-availability, waiting lists or financial consequences.

3) Attention for externally influencing factors during the continued care period

The need of specific attention to contextual factors and provision of tailored care is clearly expressed. Examples are the need of adequate living and working conditions and information to friends or colleagues to decrease social pressure to drink.

Model 1 depicts the positive aspects that need attention during aftercare period.

The model shows how internal facilitating factors (octagonal shapes) could be guided by central process of care objectives (oval shapes); facilitating organisational procedures are: the organisation of contact with peers, answering partner needs, availability of a professional care provider in the aftercare groups. Dangers in the process of care (inversed triangles) are too fast reduction of contact frequency in aftercare and to quickly involving new clients in the aftercare groups.

The model depicts how these factors are related as expressed in patient's focus groups. Following quotes illustrate some of the issues forwarded.

Relevant quotes

Aftercare group breaks the feeling of loneliness

*“We hebben daar ook goeie *contacten uit over gehouden*: mensen die we nog trouwens nog altijd regelmatig ontmoeten op regelmatige basis, een groepke.”*

Aftercare group acts as a reliable safe haven

- *“Ik heb hier 4 maanden verbleven en voor mij was dat mijn thuis komen. Nu nog. ...hier hebben ze mij enorm geholpen. Waarom? Ik heb een medisch probleem waardoor ik hier*

allé ik beginnen drinken ben. Ik ben eigenlijk beginnen drinken in het ziekenhuis, Ja, wat moet ik nog zeggen, dat was hier mijn thuis.”

- “De laatste keer heb ik dus gekozen voor de koppelnazorg. De laatste opname daar. De andere opnames heb ik geen nazorg gedaan. En daar ben ik wel heel tevreden over. *Niet alleen voor mij, maar ook voor mijn partner* vind ik dat heel belangrijk, de koppelnazorg.”
- “Mijn eerste opname dateert van 2002, de laatste van 2009 maar ik ben nu toch al een drietal jaar nuchter. *Ik heb ook altijd nazorg.* Ik ben een paar keer tussendoor hier wel terug geweest, maar de laatste dus van 2009 tot 2012 waren er ook een aantal hervallen, tamelijk ernstig, maar toen had ik *mijn familie al om er bovenop te geraken.* Maar ik kon wel ook *hier terecht* voor de nazorg. En ik kom ook nog *altijd naar dokter ...*”

Peer support helps...but under professional guidance

- “beseffen dat je er *niet alleen* voorstaat.”
- “omdat ik in de nazorg *mijn ei kwijt kon.*”
- “om mijn *verhaal te kunnen doen en ook om naar anderen te luisteren ...* ge gaat daar elke keer weg met iets nieuws dat ge oppikt‘kijk ik ben niet alleen’. ... dat zorgt voor enorm veel steun.”
- “... twee jaar nazorg gevolgd: de manier waarop dat dat gebeurt, de vrijheid die ze u laten om al dan niet uw ding te doen of te delen met anderen of gewoon aanwezig te zijn; *die begeleiding daarrond ...*dat is dag en nacht verschil tegenover de AA-groep.”
- [Over Sint-Kamillus in Sint-Denijs Westrem] “dan heb ik ingezien dat nazorg essentieel was. Het belangrijkste was dat dat met de dokter aanwezig was, voor mij toch. Een dokter die toch wel een *zeker gezag uitstraalt.*”

Partner involvement

EX-PATIENT : “Je wordt opgevolgd, maar *degene die thuis achterblijft*, zij het nu de man of de vrouw, die *staat voor alles alleen voor*” (GROEP 1)

ECHTGENOTE : “Ik zit dus ook met mijn problematiek daarrond, want ik heb ook mee ondergaan, maar u (de patiënt, nvdr.) wordt geholpen en *ik zit ook nog altijd met mijn ook kwaadheid, voor wat er is gebeurd. ...*” (GROEP 2)

EX-PATIENT : “*Tijdens de behandeling*, dat moeten we een beetje toegeven van zij heeft altijd redelijk veel *op een zijspoor* gestaan.”

EX-PATIENT : “Allé voor mijn vrouw was dat [de koppelnazorg] een heel goeie ervaring...zij werd betrokken bij alles. Wat tijdens de opname misschien iets te weinig was, dat is nu heel veel feedback en ... dat ge vrij kunt praten ... voor mijn vrouw.” GROEP 2

Promoting continuity when aftercare ends

Continuing specific support

“...nood aan assertiviteit die hij hier volgde. Nu is hij inderdaad *op zoek voor iets gelijkaardigs*, maar dat te vinden is niet zo evident ... de behandeling die hier gegeven wordt, is zo specifiek”

Preventive restart of aftercare without rehospitalisation readmission?

“ ..., als ge ne tijd ontslagen zijt uit de nazorg[groep] en ge denkt dat het weer problematisch gaat worden, dat er misschien terug een mogelijkheid zou zijn om terug weer aan te sluiten bij een groep zonder een opname te hebben maar bij een nazorggroep om toch bijvoorbeeld twee jaar later nog van te zeggen ‘ik ga problemen krijgen, het zou misschien nuttig zijn”

Experience expert tasks insure maintained consciousness of the alcohol problem:

- “...ik ben hier nu zelf medewerker in het ziekenhuis. Dat is ook een vorm van *bezig blijven met de problematiek en ventileren van en hulp bieden en eventueel zelf hulp krijgen*. In die zin loopt het voor mij wel verder.”
- “ ...dat is niet alleen wij die helpen voor anderen maar *het helpt ons ook recht te blijven.*”

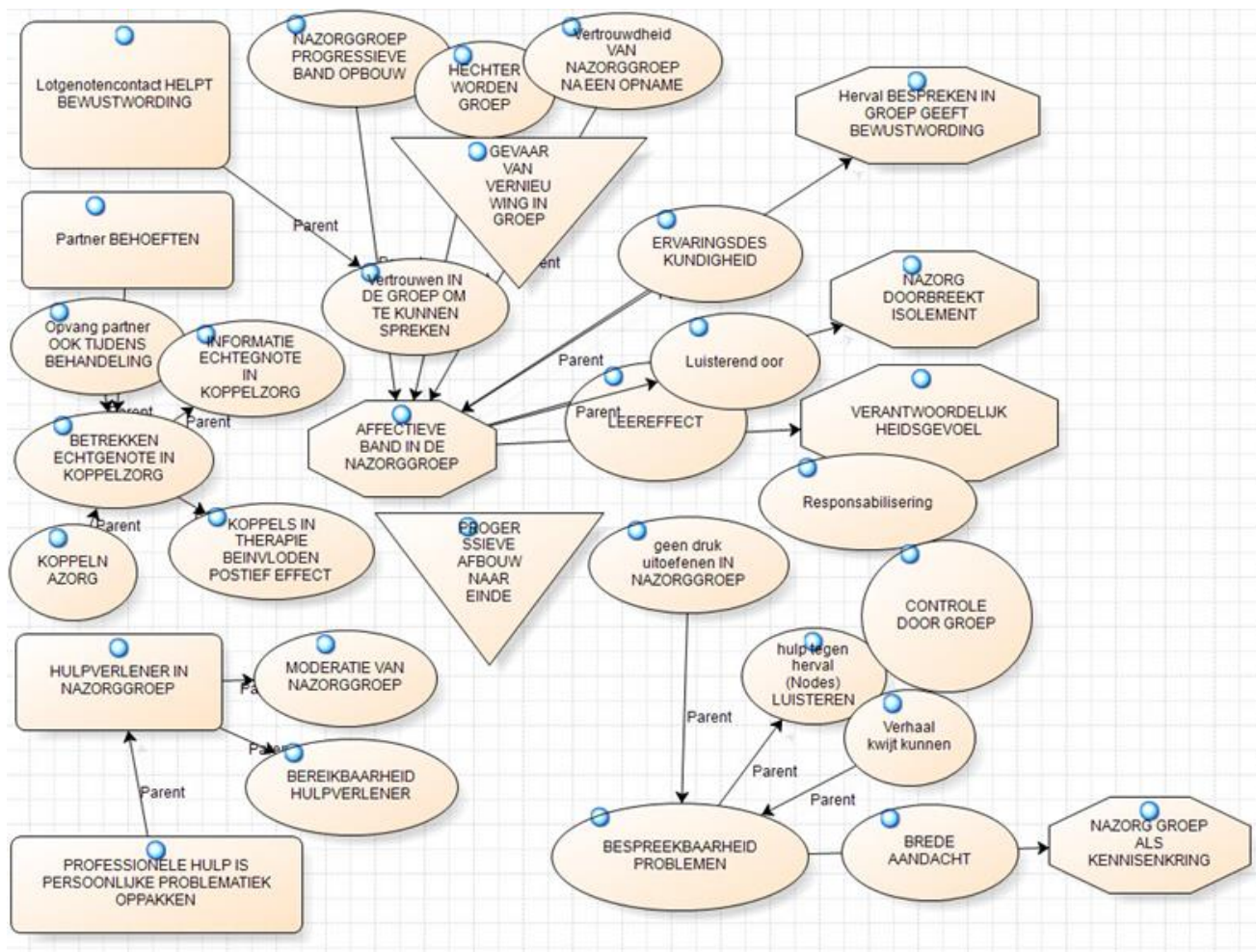
Controlling external barriers

Informing the surrounding

“Mijn ervaring is wel anders. De meeste collega’s op mijn werk die weten het zeker, in mijn vriendenkring die weten het ook wat dat mijn probleem is. *Bij de meeste mensen kan ik mijn verhaal kwijt.*”

Two models summarising facilitating factors and barriers for good care

Model 1. FACILITATING FACTORS IN AFTERCARE (ACCORDING TO LAY PARTICIPANTS)

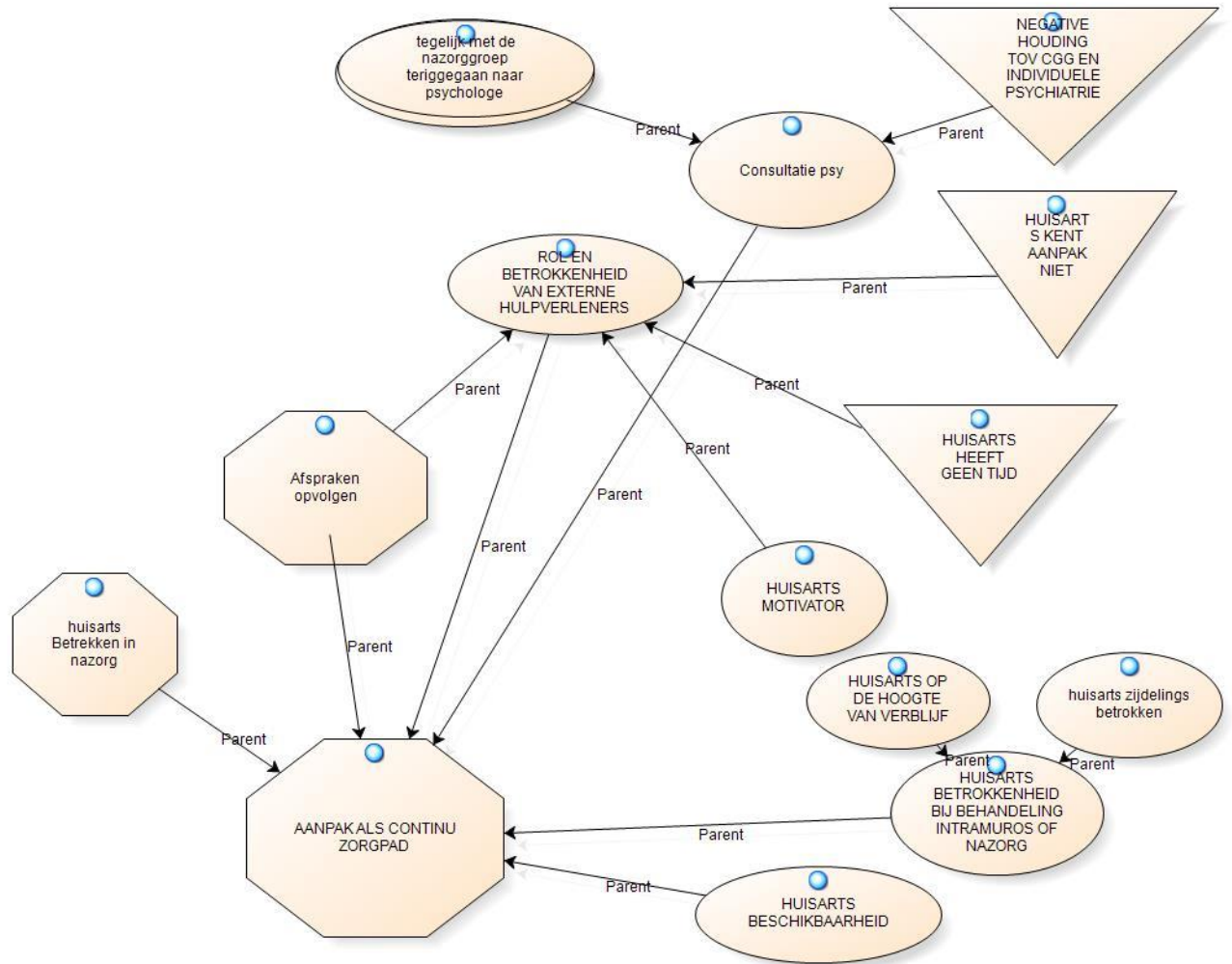


Main retained facilitating factors are according to lay groups:

- Professional support for responsabilisation of each individual
- Favours reflection about personal experiences in a protected environment with resilience for relapse incidents
- Aftercare peer group support
- Involving relevant others (partners etc.)
- Availability of easy accessible professional support in the aftercare period

Model 2 Barriers indicated by patient groups influencing the needed continuity..

Ellipses are factors that were valued positively by participants; octagonal forms indicate functions of centres facilitating better care; inverted triangles indicate problems to be solved by regional public action.



In this graphical illustration the inverse triangles indicate that according to participants in the aftercare 'external professionals' are generally insufficiently involved and inadequately informed about the care process. This was the case for general practitioners as well as mental health workers.

However, other statements illustrate the possibility of general practitioners to act as important motivators for admission and follow-up of clients.

We conclude that, according to lay participants, ambulatory caregivers need to be actively informed about hospital detoxification procedures and considered for tailored support and follow-up during the aftercare programme.

Psychologists in particular could support concomitant problems in ambulatory care if this is jointly agreed and initiated or planned before release. General practitioners can provide a more comprehensive biopsychosocial support controlling e.g. for medication (if provided) and risks for relapse; Active information is needed; they should however be interested and make time.

II. Views on continuity of care (view of lay and professional groups)

According to the model combining patient and provider views attention should also go to organisational issues and the variety of problems from a medical perspective as shown in the combined model on barriers beneath.

In the discussions continuity of care appeared under several main concerns: Drop out, relapse and need for more continued care. Transition between different phases of care need special attention (prehospitalisation, detoxification and the episodes after were discussed readily in both types of FG).

Psychiatric nurse: 'Waarbij dat we inderdaad ook merken, zoals u ook beschrijft, die overgang van residentieel naar ambulante is eigenlijk een heel heikel punt. Ze belanden dikwijls tussen twee stoelen.'

continuity interrupted because of waiting lists

Patient: "Ik heb nu ook contact opgenomen met centrum geestelijke gezondheidszorg om dan mijn behandeling opnieuw, om dan opnieuw psychologische begeleiding te krijgen maar er is een wachtlijst van 7 tot 8 maanden."

continuity of caregiver is missing

Psychiatrist : « L'aspect de continuité chez nous c'est un peu plus complexe dans le sens où c'est un service qui accueille des personnes de différentes pathologies et que le réseau pour la polyclinique pour pouvoir suivre en consultation les personnes est vraiment très petit, très réduit. Comme on travaille beaucoup avec des assistants (PG) et on change toutes les années, alors un suivi vraiment à longue durée ce n'est pratiquement pas faisable et ça c'est quand même dommage »

Patient: "Dus dat het veranderen van hulpverlener ook dikwijls resulteert in afhaken."

Psychiatric nurse: "Ik denk binnen ons ziekenhuis is dat zeker een gemis dat we niets heel specifiek hebben naar nazorg aanbieden. En dat is een puur praktische overweging geweest bij gebrek aan middelen en ook dat is al vrij veel aanwezig in de provincie dus dan gaan we daar ook niet op inzetten. Wat voor sommige mensen wel een mankement is want bij sommigen voelt ge dat ge ze eigenlijk zou moeten blijven vasthouden en het verbreken van die band, het verwijzen naar is soms voldoende om af te haken he."

comorbidity is undertreated

Psychiatric nurse: "Waar we ook soms merken dat het misloopt is wanneer bepaalde personen zijn opgenomen met een bepaald product dat er heel veel de nadruk ligt op dat product en minder de nadruk op andere dingen bijvoorbeeld dat ze ook gokken maar dat er niet op gewezen wordt zeker niet meer gokken. Maar dat we dan merken als ze op ontslag gaan dat alcohol niet zozeer iets is waar heel hard bij stilgestaan is en dat het daar dan wel fout kan lopen. Ja, ik denk dat het een voordeel is van de opnames dat als ge daar binnengaat met een alcoholprobleem dat er gevraagd wordt u te onthouden van alle producten maar naar opvolging toe ligt dan denk ik vooral de nadruk op één product terwijl dat dan belangrijk is denk ik om ofwel binnen de opname ofwel achteraf is te gaan kijken van 'hoe ga je met de andere dingen om?'. Want soms zie je toch wel een verschuiving van middelen.

dropout

"Maar er zijn ook veel mensen die beginnen aan de nazorg.. 1: En die het niet volhouden. 3: .. maar er zijn er weinigen die het volmaken. VZ: en hebben jullie een idee wat maakt dat..? 6: Dikwijls hervallen onder andere. Maar ook mensen die .. 1: Werken. 6: Door praktische omstandigheden. Maar ook mensen die niet meer.. 1: Te ver, te ver..... 6: Verschillende factoren eigenlijk. "

poor integration in care group

Patiënt "En ik ben toen een paar keer gekomen en toen was dat eigenlijk wel moeilijk om in die groep te geraken."

Patient: "Omdat die groep al te lang samen was. Dat is wel zo. Waarschijnlijk ook niet goed dat de groep te lang, te oud wordt zagezegd. "

relaps stigma

Psychiatric nurse: "Mensen zeggen heel vaak we slagen er niet in, dat gevoel van falen, en schaamte en schuld en weet ik veel wat allemaal dat dan opspeelt."

Psychiatrist: "Want ge voelt dat daar heel veel mensen toch zo die schaamte hebben van oeh ga ik die nu niet lastig vallen en ze hebben mij eens zoveel maanden geleden geholpen en nu moet ik dan met hangende pootjes.."

Psychiatrist « la rechute est rarement considéré comme fessant partie intégrante du processus de thérapeutique, et généralement elle est un peu criminaliser. La personne a consommé donc limite elle est exclue du centre avec la décence au enfer que ça peut engendrer »

Insufficient knowledge of specialised care (options)

General practitioner: "En wat is er nodig? Hoe kunnen we dat ondersteunen? Wij hebben daar zo geen zicht op. Misschien moeten we daar niet in aanwezig zijn? Dat kan. Maar we weten het niet en dat is jammer."

III. Towards a model for improvement of continued care

The analysis of barriers leads us to the main model for further improvement of care based on the focus group analysis.

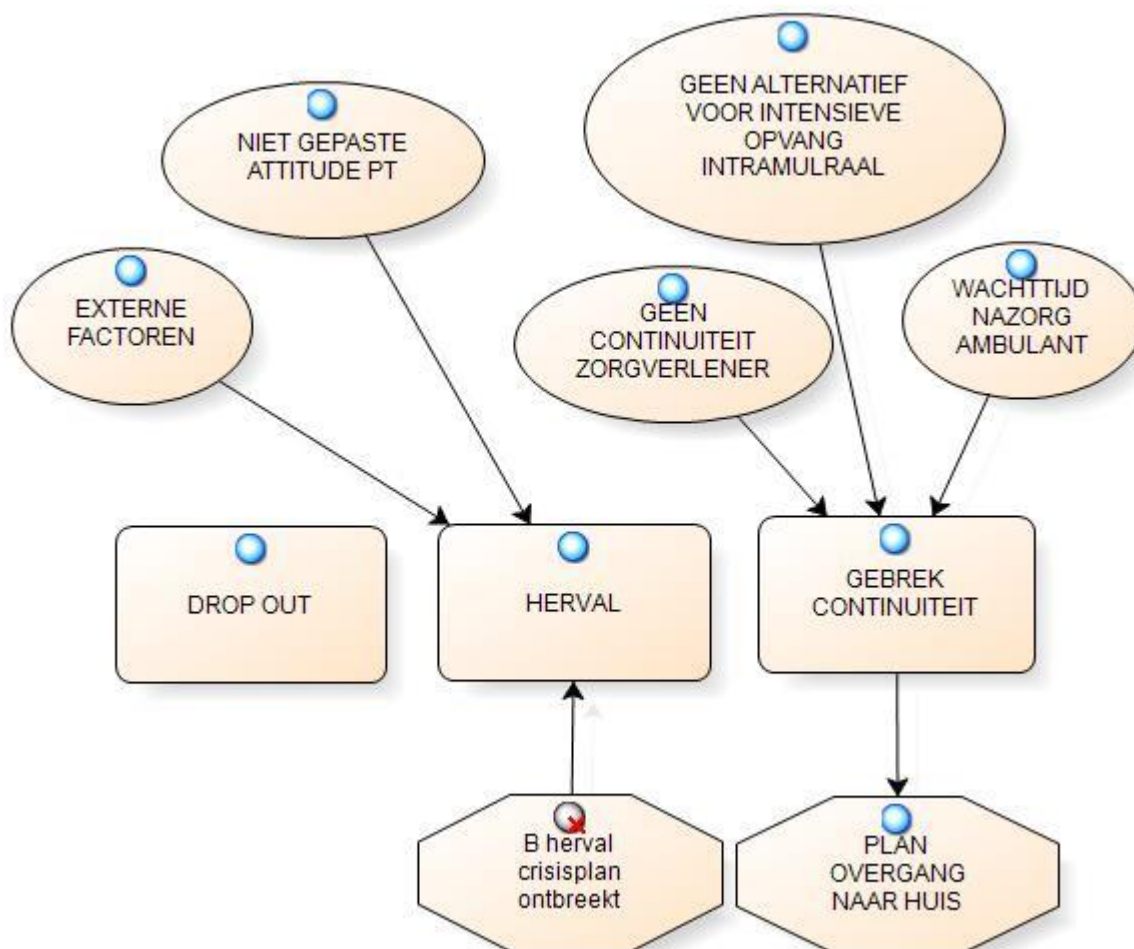
Main factors retained for further action in patients and caregivers focus groups are largely similar and depicted in following two graphical representations of a combined model.

Central concepts

Main concerns expressed in both lay groups and professional groups are patient drop out, relapse, and lack of continuity of care.

External social factors, attitudinal and behavioural aspects need to be controlled to prevent relapse. Organisational issues such as continuity of caregiver, reducing waiting time for adequate care and providing alternatives for tailored in-patient care are prioritised structural improvements. The core of such a model is depicted beneath:

Model 4. Core concerns in continued care after detoxification



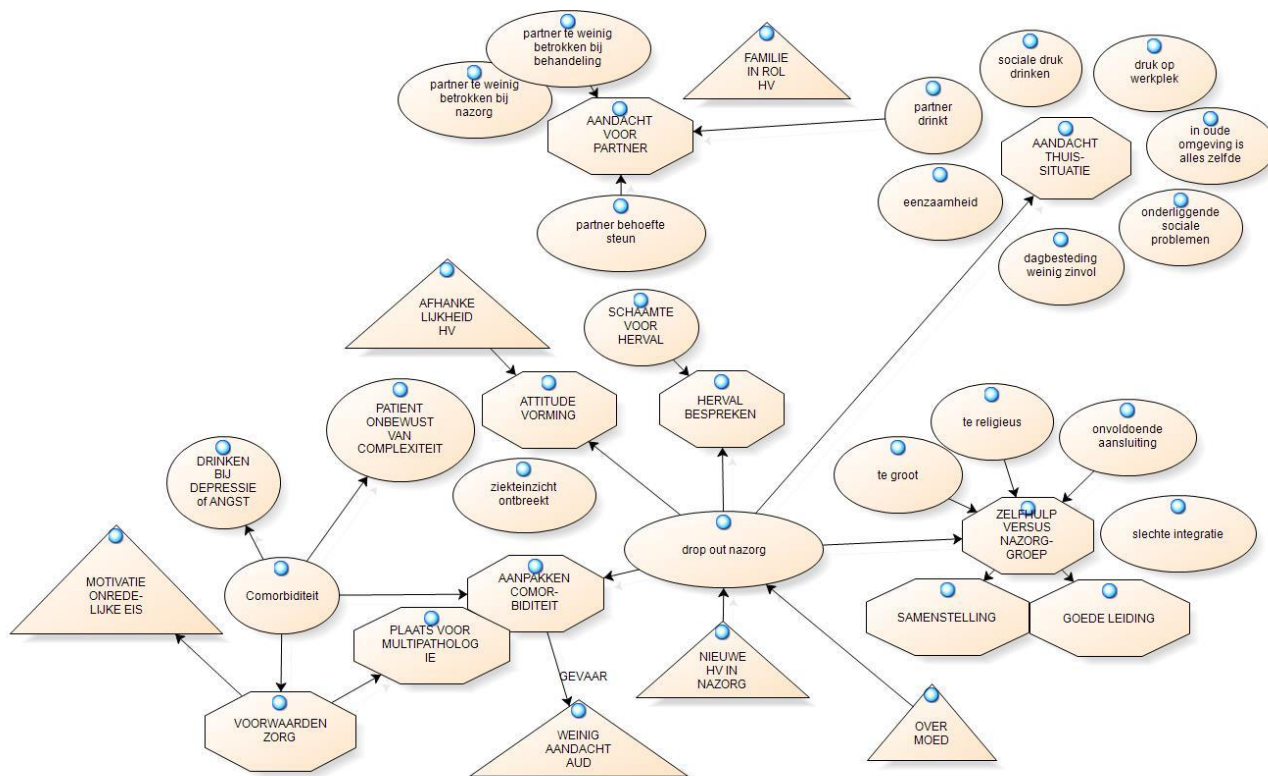
To avoid drop out, organizational aspects such as providing continued professional support and aftercare or self-care groups for peer involvement and personal tailored support, is needed. Tailored care is facilitated by the right patient attitude incorporated through cognitive change favouring an open attitude towards reflection and open discussion of relapse incidents, as well as by paying attention to potential comorbidity and underlying social factors.

Returning home means dealing with numerous factors, which may impede abstinence, as depicted in the right upper corner of the graphical display of the model.

Another important aspect is the family context. This can be dealt with (e.g. by involving the spouses early in the care process); when needed personal support should also be given to the spouse e.g, when they also have a drinking problem.

Model 5. Problems and related functional requirements for tailored care

On an individual care level avoiding drop out, preventing relapse, dealing with multiproblem situations socially (home, work and family) and medically (comorbidity, personality and attitudinal) (according to lay and professional groups):



In the above model, octagonal forms represent functional requirements for episodes after detoxification. Circles are problems to deal with and triangles are dangers to which providers must be attentive during continuous care.

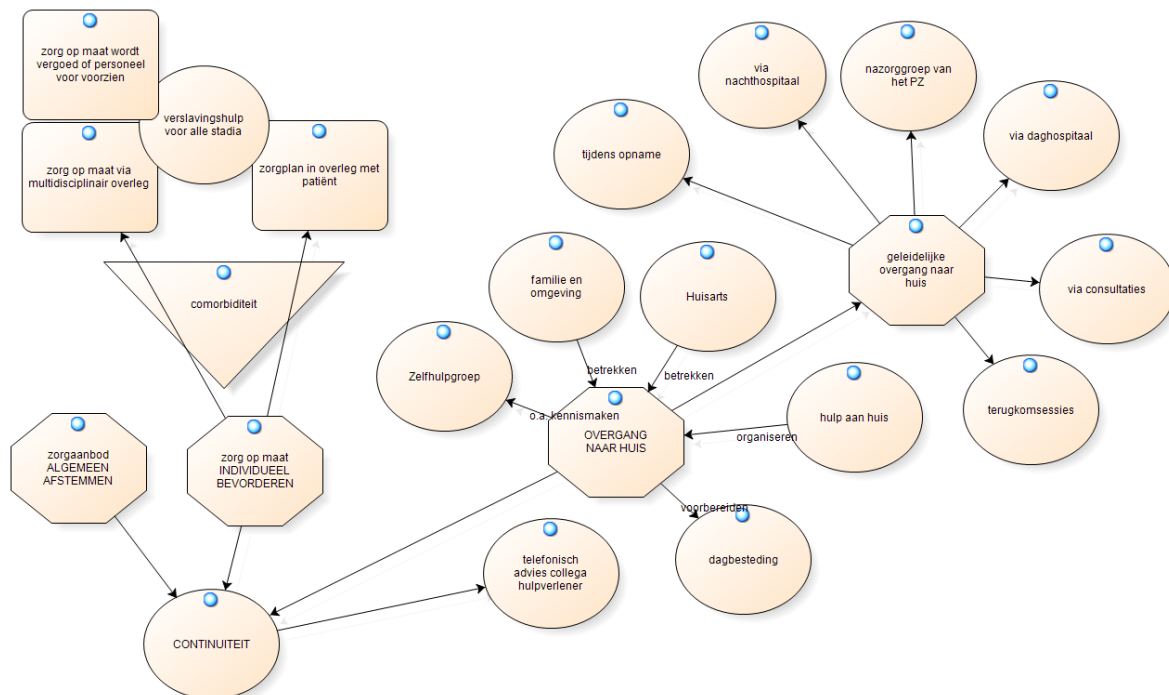
Orienting individualised care provision

How this can be performed is further apparent from the analysis of the specific fragments of aftercare in providers focus groups as depicted in the last model beneath. It introduces a new number of aims for the care process as depicted as octagonal forms:

1. Tailored care according to expressed needs of clients and their relevant others
2. Preparing transition between episodes of care from the points of view of care, care providers and organise this as a gradual experience allowing for resilience and relapse
3. Improving communication between providers involved

Model 6. Planning the transitions in tailored individual care

By matching French and Flemish terms (e.g. 'nazorg', 'cure' and 'posture'), an independent new analysis in two steps, first by constant comparative coding (DZ), then consensus building (DZ, LP) yielded a refined three of codes specifically for aftercare view of professional providers. This yielded a model specifically based on quotes of the caregivers' focus groups, leading to the concepts on continued individual care as depicted below.



Octagonal forms represent functional requirements for aftercare ('general collaborations and knowledge of existing care', 'tailored care' as well as 'transition to home'). Comorbidity (inverse triangle) complicates tailored care. Addiction aid for all phases, including relapse (circle) is suggested for tailored care and could result in a more continuous care.

Requirements at structural level

Tailored care and communication requirements also indicate special attention for structural aspects of care (e.g. meaning that regional care facilities should cooperate more intensively to allow a chain of continuous care for the variety of problems which may exist or occur during the different care episodes).

To realise these targets, the rectangles in the last model indicate additional organisational features for centres, which should be taken to develop effective continuity of care (see model):

- Regional multidisciplinary coordination
- Support for personalised care planning

- Maintaining contact with (individual) care providers with activity independent of the detox facilities
- Involving external aftercare peer groups and caregivers during intramural care to get acquainted with the clients and vice versa.
- Reducing waiting time for outside support
- Providing facilities in the aftercare period to reach the care team

Related Quotes on facilitators to continuity of care

Regional multidisciplinary coordination

Social worker« Nous c'est vraiment un réseau de partenaires, en région Wallonne et bien sûr aussi en région bruxelloise, et ses partenaires, touche de près ou de loin à l'assuétude. Donc il y a des services très généralistes tels que des maisons d'accueil comme la nôtre. Des services beaucoup plus pointus tels que des services de post cure, ou de cure. Donc ça va vraiment de services très généralistes à des services vraiment généraliser et donc effectivement tous les mois, ses institutions se regroupe et aborde des situations qui sont donc intégrer dans ses réseaux et on essaye de réfléchir à une trajectoire de soins, la plus adéquate et la plus fonctionnelle pour la personne. Bien sur la personne doit être d'accord avec ça, ce n'est pas une chose qui lui est imposer, il a la possibilité de refuser ce qu'on va lui proposer. Mais c'est qui est super important dans ces réseaux, c'est que chaque partenaires ce fait confiance et que chaque partenaires ce connais, et donc va pouvoir orienter la personne en connaissances de cause et en connaissant la finalité et le projet pédagogique de l'institution vers la quel il va être envoyé. Et je pense que c'est ce qui permet une réussite vers la postcure. C'est de vraiment envoyer des gens en leurs disant ou ils vont et ce qu'ils vont y faire.»

Support for personalised careplanning

General practitioner: Ge hebt het multidisciplinaire overleg maar dat bestaat ook voor psychische problematiek dat is eigenlijk een manier van gesprekken te organiseren waarbij ook huisartsen gefinancierd worden zal ik maar zeggen. Verloning voor krijgen. Dat we bijvoorbeeld voor fysieke zaken kan dat door iemand van de mutualiteit georganiseerd worden maar ik denk ook evengoed voor psychische problematieken.

Psychiatrist: "En daarnaast ook een beetje op vraag van de patiënten bespreken we dat in welke mate de huisarts eigenlijk een rol kan spelen. Want dat is eigenlijk ingebed in het hele nazorgtraject van wat mensen dan eigenlijk wensen, wat ze niet wensen. Sommigen kiezen ervoor om alleen naar de huisarts te gaan, sommige zeggen we komen nog wel eens ambulantly bij de psychiater of ik heb iemand anders ambulantly. Sommigen gaan naar het CAD, sommigen gaan naar de AA, sommigen misschien zelfs een grotere meerderheid die zegt van ik ga het zo proberen."

Psychiatric nurse: "Wij hebben ook een ICM project gehad, intensive case management. Dat is een project samen met ... en met Pelgrim. Nu die financiering is gestopt maar wij hebben

beslist om dat verder te doen. Dus mensen die moeilijke familiale omstandigheden hebben of comorbiditeit die kunnen in intensive case management komen gedurende een jaar waarbij dat zij heel regelmatig opgevolgd worden. Meestal is dat door hun hoofdverpleegkundige, die ook aan huis gaat.”

Maintaining contact with (individual) care providers with activity independent of the detox facilities

Psychologist : “Et donc là dans mon expériences, le fait de revoir les patients, par le biais des urgences, par le biais des consultations, et de leurs reposer une hospitalisation quand on estime que c’est pertinent et puis les laisser réfléchir et prendre une décision. Il m’arrive parfois qu’on m’envoie des gens, et il me faut 3 entretiens répéter à des moments différents pour que les patients commence à écouter ce que j’ai à lui proposer comme type de soins ou de prise en charge. Et là en général, indépendamment de la gravité ou de la personnalité, les choses se passent nettement mieux. Parce que j’ai eu l’occasion de lui donner la brochure, de lui montrer le service, j’ai pris le temps de lui expliquer un peu la philosophie de travail, les règles. J’ai expliqué ce qu’on attend de la personne, ce qui prend aussi du temps. Et là c’est plus évident.”

Involving external aftercare peer groups and caregivers during intramural care to get acquainted with the clients and vice versa.

Psychiatrist : «Donc je crois que le contact d’un service qui va prendre en charge est très important. C’est pour ça que les questions de mettre des autres projets qui font encore une fois six semaines un relais. Donc le patient va d’un relais à un autre. Il en a marre. Et donc moi je crois, là je parle pour l’ambulatoire, ils devraient se dépasser un peu plus facilement. Surtout en ambulatoire. Ils devraient se déplacer, ils devraient prendre le temps et je crois que là on arriverait déjà à mener la personne d’une place à l’autre. Ça ne marche pas de donner un coup de téléphone, ça ne marche pas de donner une petite carte avec un rendez-vous. Ils ne viennent pas, et si nous on ne connaît pas le patient. C’est embêtant, mais quelqu’un qui n’a jamais vu, on n’est pas tenté de lui téléphoner pour demander ce qui se passe. Si c’est quelqu’un que tu connais et qu’il ne vient pas, et bien alors on téléphone. Je crois que ça peut améliorer le suivi à long terme de quelqu’un ».

Psychologist : « Nous avons aussi fait pas mal, en tous cas dans la région de Charleroi, c’est nous qui allons présenter la postcure dans l’hôpital. Et donc à l’hôpital ils organisent une séance de deux heures, et peuvent participer ceux qui sont intéressés pour la postcure. Et à ce moment-là il y a 5-6 personnes et ils posent toutes les questions ; Donc on vient avec des documents, avec des photos, des choses très terre à terre. ‘Et ma chambre elle sera comment ?’ Voilà, ça c’est les chambres, le jardin. Aucun membre ne dira c’est très bien. Non ce n’est pas suffisant. J’ai vu les deux donc les gens qui viennent dans le centre et le centre qui va à l’hôpital. Moi personnellement je suis plus pour que ce soit nous qui allons déjà à l’hôpital. Parce qu’il y a quelque chose. La personne a déjà fait une grande démarche pour se présenter et quand on y va quand il est déjà en hôpital entrain de faire le sevrage, il est déjà dans un processus. Et donc c’est important dans ma vision à moi de faire l’accroche à ce moment-là pour la suite ».

Psychiatric nurse “Wij gaan ook, dus wij doen drie modules. Ons behandelprogramma bestaat uit drie modules. De laatste module. Eigenlijk wordt er al van vrij snel rond nazorg gepraat

maar concrete uitwerking is in de laatste module. Mensen van AA worden uitgenodigd, mensen van SOS nuchterheid worden uitgenodigd”

Psychiaterist:”Patiënten de gelegenheid ook geven om in contact te komen met de ambulante, soms eventueel meegaan, om de stap te vergemakkelijken. Want wij zien toch inderdaad rond continuïteit wel dikwijls een probleem. Dus dat het veranderen van hulpverlener ook dikwijls resulteert in afhaken. En dat is wel een probleem.

Reducing waiting time for outside support

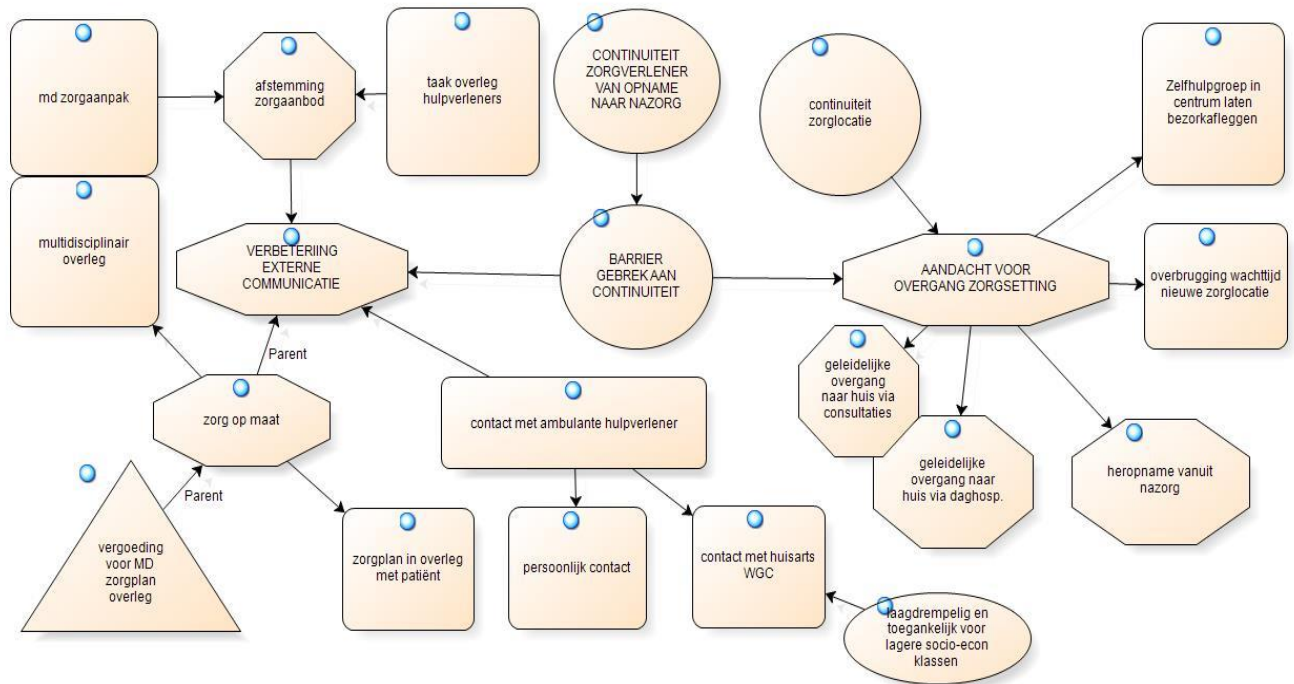
Psychiaterist:”ik weet dat ik zo het principe heb van als mensen al de voordeur binnenkomen moet ge kijken waar de achterdeur is. Dus vanaf de eerste week dat ze bij mij komen begin al te praten over nazorg. En ik ondervind dat dat voor heel veel mensen heel vreemd is, dat ik daar al mee bezig ben. Dat ze dat soms wel bedreigend vinden van ‘laat mij eikes eerst op mijn positieve komen voor dat ge al spreekt over daarna’. En ook dat dat blijkbaar not done is of toch niet in de mate waarin ik het doe. Ik denk dat dat inderdaad iets is waar nog niet altijd genoeg aandacht voor is.

Providing facilities in the aftercare period to reach the care team

Psychiaterist : »Quand ce système-là ne marche pas, il est important que quelque part les médecins et l'équipe de soignants laissent la porte ouverte pour revenir parce que c'est souvent dans la répétition des contacts et leur durée que ce mode accroche et que une confiance Et là ça le rend réceptif à une exposition plus élaborée mais alors c'est encore à la charge du soignant de savoir 'Je vous propose ceci parce que cela, cela, cela. Je ne vous propose pas ceci parce que, ceci, ceci, ceci. ' Donc vraiment déjà une logique d'aiguillage”.

Psychiaterist: Maar het is inderdaad een vorm van nazorg he. Het feit dat men gewoon kan binnenstappen. Eigenlijk is dat bij ons ook in het algemeen ziekenhuis. Ge werkt nooit niet met wachtlijsten. Dus ze bellen en zeggen 'ik ga hervallen' dus ook het beschikbaar zijn, laagdrempelig, kun je ook als nazorg zien. Als continue zorg. Want het is een chronisch probleem natuurlijk.

Model 7. Reorganizing care structures to increase continuity of care



III. Discussion

Due to the scarcity of studies on continued care after detoxification, even with our systematic review taken into account, there isn't a sufficient basis for a continued care protocol. To improve the outcome of care after detoxification, consensus indicators have been developed based on guidelines for care. Furthermore, the actual provision of care was investigated by online enquiry. The current study complements those previous works by investing views of practitioners and participants to care for AUD in the two main linguistic communities of Belgium.

Main hypotheses

Views of participant lay people as well as care givers orient us to a clear vision on quality of care strongly related to the chronic nature of alcohol dependence and its underlying problems, hence the need of good and long lasting thrust and continued provisions for care.

Main issues forwarded by the participants were depicted in schematic presentations indicating problems to cope with, important functions and intermediate goals for care as well as practical ways to achieve them. The main concerns are:

1° Lay and professional participants both recognise the chronic nature of alcohol dependency and underlying problems, hence the need for better continuity of care taking into account multiple domains of living

2° All different participants stress the need for better communication and care coordination between prehospitalisation care providers, staff of detoxification units and the following (ambulatory) care providers.

3° On the individual care level

- Quality should be pursued through measures ensuring better knowledge and communication between ambulatory and residential care.
- Measures to provide a more rapid (re)access to residential care when (at risk of) relapse or to access ambulatory care at discharge (e.g. online support, telephone contacts, gradual transition facilities)
- Measures should be taken to allow access of lay carers to professional support.
- Organising access as well as support of informal care providers, including spouses or relevant others as well as volunteers of self-help groups should be part of institutional protocols.
- It does not make sense to provide individual tailored care at institutional level and then release the client while on waiting lists for continued professional support.

4° A number of measures at hospital level and regional level are needed to set the framework for such coordination, which were not described from the guidelines as criteria for good quality care. These measures however are important structural quality criteria. A policy may be needed to implement them, but piloting these aspects should at least be pursued. Some existent methods and facilities can be used (zorgplannen en -trajecten, samenwerkingsinitiatieven eerste lijn (sels en GDT), reseau WaB and others)

- Professional information on care facilities and continuity of care measures
- Multidisciplinary task discussions
- Contact facilities with ambulatory care professional and lay care providers and clients during the detoxification period
- Reporting principles

Quality criteria of the care process

Finally we draw following conclusions on the care principles forwarded in relation to the indicators stemming from the preceding Delphi Study (see table).

The indicators for quality of care (table 1) from the Delphi study can be complemented by specific advice about the related care process based on the main findings of the current study.

Indicator 1

Self-help or aftercare groups should be made accessible to patients in detoxification programmes.

Early contact during detoxification period with members of self-care groups is suggested. Representatives of self-help groups might be encouraged to visit detoxification units in a systematic way; alternatively, caregivers could accompany patients to meetings. A 24h 7/7 days

available online forum was also proposed as effective peer-to-peer aid, often enabling a franker and more direct interaction than possible with a professional therapist.

Aftercare self-help groups should be well moderated and allow free discussion of problems between peers.

Indicator 2

Relapse prevention needs to be based on individually tailored support and promote open discussion about episodes of relapse and cope with shame due to relapse; relapse should not be considered a failure but an experience to learn from. One specific aspect of relapse prevention is the gradual transition to the home situation. Psychotherapist could even accompany patients on their first steps in their regular living situation; resilience about craving incidences should permit discussion in group sessions. Family or significant others can be involved to prepare the return home; they also should be prepared to the possibility of relapse and coping strategies.

Indicator 3

Not only involvement of patients in aftercare is important, but involvement of partners as well; they should not be imposed to function as care givers but be seen as part of the family system which also needs specific support; the proportion of clients with family members involved which get support might be an additional criterion. When patients prefer complete secrecy (e.g. exclusively counselling online) caregivers suggest to motivate the patient to inform at least one person of confidence about the AUD in his surroundings.

Indicator 4

Continued psychosocial support should be provided during institutional care as well as after discharge from hospital. In particular, similar targeted support according to needs should individually be available in ambulatory aftercare as during institutional care. Specific attention should be given to external context of the client to prevent relapse due to external factors.

Indicator 5

Even after an episode of aftercare is ended continued awareness and easy readmission remain important; long term care does not end after an aftercare episode is closed, neither be it due to drop out or due to rules about duration of the aftercare episode (e.g. is some centres 2 year, in some shorter).

Indicator 6

Caregivers rarely check if the patient made the transition to the care facility they were referred to. It is advised to inform the care facility and return information of no show. This allows the referring caregivers to contact the patients.

If patients feel more and more stronger they tend to relapse; this may very well happen around 3 month or later; therefore, reassessment and active follow-up is certainly merited at 6 months and later although the indicator was set at 3 months during the preliminary Delphi round.

Indicator 7

Alcohol moderation was rarely discussed during patient groups as participants indicated that they thought them risky. Limited quotes were also found on the providers' side. However, drinking with moderation has more and more become an accepted choice, mostly to intensify a bond with the patient, enabling motivation for total abstinence when necessary. A care plan should be developed in accordance with the patients about moderate consumption versus abstinence;

Indicator 8

Tailored individual care is needed; care after discharge cannot be done without patient consent obviously. This means that the patient is actively involved in the choice of individual and/or group therapy, in residential as well as in ambulatory setting.

A limitation of this criterion was mentioned for clients under probation treatment due to law enforcement.

Table 1. Indicators of continued care form Delphi study (Bekkering et al. 2015)

1. If a patient was informed on a self-help group for alcohol misuse.
2. If psychosocial relapse prevention strategies are used.
3. If patients that agreed to involve the environment in aftercare, the proportion of patients for which the environment is actually involved.
4. For patients that receive medication, if the patient also receives psychosocial interventions.
5. If during the process of detoxification, the patient is informed about the importance of long-lasting involvement in treatment.
6. If patient is followed at least 3 months after their discharge.
7. If harm reduction strategies are used in patients that opt for moderation.
8. If the aftercare plan is developed in consultation with the patient.
9. If the patient received any professional or non-professional aftercare within 14 days after discharge.
10. If the patient is satisfied with the quality of contact with his care giver(s).
11. If the patient is abstinent at three months after discharge.
12. If the patient functions well at three months after discharge.
13. If the patients feel well mentally at three months after discharge.

Indicator 9

Professional support is needed besides self-help groups; exclusive lay support as continuing care measure may need to be evaluated but was not suggested during FG.

Indicator 10

One should be careful with applying this indicator. Indeed, focus group lay-participants confirmed the necessity of a good therapeutic relationship with the caregiver and quality of contact with his care giver(s) is important. However, satisfaction with aftercare relies on many more issues than the quality of contact with the provider. Caregivers also indicate that a therapeutic bond and trust are important, and that this should even prevail over concrete therapeutic goals. Since the patient has to overcome his shame to work with relapse situation, increasing thrust may arise from several incidences of relapse.

Indicator 11

The long term duration of the chronic dimension of alcohol dependence merits long term follow up

Indicator 12

Good functioning means that during the continuing care process attention is oriented to all relevant life domains: useful daytime activities and/or thoughtful (re)integration in work setting and in social networks should be aimed at during therapy.

Indicator 13

Comorbidities need specific attention.

Strengths

Interpretation was performed using a constant comparative analysis working in pairs of independently interpreting coders confronting the interpretation from different professional backgrounds (public health, psychiatrist, general practitioner, addiction specialist). The variety of different professional groups involved (nurses, psychologists, psychiatrist, general practitioners, addiction specialists and others) as well as patients, ex-patients and their informal care givers allow for a large variety of views and varied frameworks for interpretation.

Providers on the other hand come from a variety of settings in general care (PAAZ), specialised detoxification units and a variety of aftercare settings including therapeutic groups, and law enforcement based care.

Generalisation of generated hypotheses and suggestions for improvement are based on involvement of care providers from two linguistic communities.

Limitations

Due to practical reasons (adding this to the tasks of the original protocol) this study is somewhat limited by the small number of lay FG and the absence of French speaking patient groups. The apparent similarities of concepts forwarded however in both linguistic communities and among lay focus groups and provider groups support their general applicability.

Another limitation may reside in the uncertainty about saturation of new codes linked to two FG of patients with similar positive views of aftercare. No information was collected from clients who dropped out aftercare programmes, although many of the participants in this study were readmitted to the hospital several times, which made them experienced in drawbacks and dropouts. In developing or adapting actual protocols for care this limitation should be taken into account and information of non-attenders in aftercare may be needed by interviews or other means.

IV. Conclusion

This study fills a gap of knowledge on views and priorities of continued care after detoxification for alcohol dependency. Using a constant comparative analysis by a multidisciplinary team views of (ex) patients, lay carers and different professional care providers yielded suggestions and hypotheses for quality of care.

Suggestions are made for functional aims, specific process of care targets to improve actual services, and collaborative approaches in individual care and on organisational level. We refer to the models for individual tailored care (model 5), the transition between care settings (model 6) and structural measures (model 7).

In particular care should be tailored according to expressed needs of clients, specific individual external risk factors for relapse and drop-out and including consideration for relevant others. Preparing transition between episodes of care from the points of view of care, care providers and organisations should be a gradual process allowing for relapse of clients and resilience of care providers. Improving communication between all providers and settings in continued care should be realised.

We suggest further evaluation using these principles. Further consensus development concerning implementation strategies should be continued based on a view for continuity of care between ambulatory and institutional centres, but also include the prehospitalisation, the detoxification period and a prolonged continuing care.

A descriptive overview of regional facilities should be available to inform a coordinated care pathway and protocol for coordination of individually tailored care; latter should include specific attention for the different life domains of the client systems and include the family of alcohol dependent patients in the process actively.

Organised meetings between caregivers of different settings would increase the understanding of their care facilities and enable a trust-based collaboration between professionals.

Piloting such a scheme would enhance our understanding of effective care provision for the actually neglected chronic care problem of AUD.

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